



[pauline@autismgoals.com.au](mailto:pauline@autismgoals.com.au)  
0419449551  
<http://www.facebook.com/familiesandautism/>  
ABN: 7239186869

## **The 2020 Review of the Disability Standards for Education 2005**

### **Submission**

### **Our Information through Lived Experiences.**

#### **Author**

**Pauline Aquilina**

**18<sup>th</sup> August 2020**

## Autism Goals ASD School Advocates:

### Our Philosophy:

#### THE I IN IEP/ILP

I am an advocate for your child.

I know my rights, your rights, and your child's rights in this process.

I will research all education policies relating to your child.

I will defend and fight for your child.

I will not back down over their needs.

I will never surrender their right to a fair and proper education.

I will be prepared as possible for questions

I will ensure the plan is 'Individualised' and not generic.

I will ensure the school remembers that this is about a person and not a process

(author unknown)

We believe children are our future.

We believe each and every child has the potential to bring something unique and special to the world. We believe the thinking 'outside of the box' approach of children with autism is something this world, right now, is in desperate need of.

We will help children with ASD develop their potential by identifying their strengths and guiding them to see and believe in those strengths themselves. We aim to help them to use those strengths to overcome the challenges that need to be supported.

We will strive to assist children to discover who they are, so they can express their own opinions and nurture their own ideas.

We have a vision of a world where people learn to respect, accept, and embrace the differences between us all, as the core of what makes life such a rich and fascinating tapestry.

We believe that if we help children learn, by teaching them at their point of need, they will lead the way.

To accomplish this goal, we need to build a supportive and protective team around our students so that their needs are met, and that they as learners can feel capable and successful.

We will endeavour to work as part of a team with families and the school, to develop learning goals that are relevant and authentic and that involves the interests of the child. We will advocate to have their learning connected into a context that encompasses their passions and interests.

We believe we need to show them all the beauty in the gifts they possess. To give them a sense of pride. We believe education and learning are the portals into a future where children with ASD can live and contribute to a caring, safe, and equitable society

We affirm that families and educators along with other professionals have a responsibility to help and guide children to become responsible for themselves, as well as their own learning.

We accept that advocacy team has a role to play in ensuring that children living on the spectrum have the tools to become successful in life, to believe in themselves and to feel good about themselves.

## Autism Goals ASD School Advocates:

### Our Work

My name is Pauline Aquilina and I have worked in the education field for over two decades, primarily in the student well-being area. I have worked with children on the Autism Spectrum Disorder and their families. My passion is to help children reach their full potential, which is not always maximised. This is often due to them not being able to fully access and immerse themselves in learning opportunities. It is at this point that Autism Goals: ASD School Advocates come into its own.

I began Autism Goals in April of 2018 and since then we have been inundated with pleas for help and support. Autism Goals was established because of the birth of our first grandson. As ██████ reached two years of age, it became apparent that he was displaying traits of Autism Spectrum Disorder. It took till he reached his first year of school for him to be finally diagnosed. I supported my daughter as she began her family's journey advocating for ██████'s rights to a quality education equal to that of his peers.

During his Four-Year-Old Kindergarten year, ██████'s mum approached the Early Years Educators for support for her little boy. She was turned away with, "He's from a broken home, it's a discipline issue". He was treated punitively, and his mother labelled as 'the incompetent mother'.

██████ began Prep and he had quite a successful year. He was with a young graduate teacher who had knowledge, skills, and understandings about ██████'s needs. She implemented modifications and made accommodations to assist ██████ to learn. Of course, there were moments. However, home and school, worked in partnership and ██████ developed.

██████ completed Prep and went into Year One. There was no transition program, there was no Individual Learning Plan/Individual Education Plan/Individual Learning Improvement Plan/Personal Learning Plan (I make a point of trying to include all the terminology as it is this that schools hide behind). Year One was devastating for ██████. This time he had school personnel working with him that did not share the knowledge that his Prep teacher had. Again, ██████ was treated punitively. The Year Level Team Leader recorded him having a melt down as evidence of a 'naughty' child. I walked in after a school day to pick him up, only to hear a teacher talking negatively about him to another parent.

██████'s mum made an urgent appointment with the Principal to discuss ██████'s treatment and his needs that were not being met. I accompanied my daughter to advocate for her and my grandson. Initially, it was not known that I had been a Deputy Principal. It was when I contradicted comments citing the Disability Discriminations Act and The Rights of the Child, knowledge about the Program for Students with Disabilities, Student Support Group guidelines and so on that the tone of the meeting altered and a partnership between home and school started to form again. I don't mention the Disability Standards for Education as at that point I had never heard of this document.

██████'s mum with my advocating were able to ensure that a positive home school team worked together through Student Support Group Meetings, drafting ██████'s Individual Learning Plans, reflecting on the attainment of short-term goals and implementing reasonable accommodations and modifications.

It was while I was spending time with my daughters, being with them as they incidentally bumped into friends and acquaintances with children who shared the same needs as ██████ that it became apparent that ██████'s case was not unique but the norm.

With my daughters' prompting I established Autism Goals ASD School Advocates.

## Autism Goals ASD School Advocates:

### ██████████'s Experiences Lived by Many Others:

Autism Goals is now a team of thirteen with offices in Victoria and Queensland. We advocate for clients from Western Australia, South Australia, Queensland, New South Wales and Victoria. Our clients' stories are horrific. The way to illustrate how we have a problem not only in Victoria but across the country is to tell you the stories:

A mother emailed me with severe concerns about her seven-year-old daughter (for the purposes of this retell, will call Susan). Although, she was concerned about her daughter not having access to the learning opportunities that her peers were intrinsically experiencing, she was also extremely concerned about the bullying that her Susan was facing. The parents met with the Principal and the Deputy Principal on numerous occasions trying to get someone to listen to them and support their little girl. The young girl was told that she had to stay on either the oval or the play area. The other girl would occupy the alternative school ground area. This was the accommodation implemented. The other young student stood on the edge where the two areas aligned. She put one foot on the playground and the other on the oval. Susan's anxiety heightened. How was she to follow instructions when her tormentor was on both areas, especially as she had been told that she would be the recipient of punishment if she did not follow this Principal's instructions. While at home, the bullying continued online. The parents went to the Principal who advised them that what happened at home had nothing to do with the school.

We scheduled a Student Support Group Meeting but before we could meet, Susan attempted suicide. In fact, the first attempt was not enough for the school to support this young lady. Susan said that no one was helping her and she self-harmed again.

During the meetings, I spoke about the Disability Discrimination Act 1992 and the Disability Standards for Education 1985. This staff were not familiar with either of these documents.

Another mother who has twin boys approached the school for support. The issues were that the boys have multiple diagnosis and have complex medical needs. These include Autism Spectrum Disorder Level 2 and 3 (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Sensory Processing Disorder (SPD), Anxiety, Dyspraxia, Dysgraphia.

In addition, Colin (for the purposes of this story) has the chronic and potentially life-threatening condition, Permanent Pneumothorax. As a result of this condition, Colin's lungs have been in a collapsed state on ten occasions. Due to the multitude of this occurrence, extensive scar tissue has developed on the lungs and within the chest cavity. This makes Colin is susceptible to chest infections which can and have led to hospitalisation. These medical challenges place the boys in a very vulnerable position, both physically and emotionally. Colin's position can become life-threatening rapidly.

Simultaneously, the boys' older sister Kate (for the purposes of this retell) is also medically vulnerable. Kate suffers from a genetic autoimmune disease which potentially is also life threatening. Kate is required to take Immunosuppressant drugs. These are a class of drugs that suppress, or reduce, the strength of the body's immune system. Hence, Kate cannot become exposed to others' ill health or potential ill health.

The family's extensive care team, (Haematologist, Immunologist, Paediatrician, General Practitioner and Gastroenterologist) have discussed the complex and life threatening needs of members of this family with

the family and advised strongly that it was too perilous for the boys to return to school currently. The implications are not only detrimental to the physical wellbeing of the family but also for their emotional and financial wellbeing. Any illness would result in Kate not able to return to the family home for a period. Dad works with a vulnerable community and as such needs to protect his physical wellbeing so that he can continue his work. The family depends on this one form of income.

The family had shared this knowledge with the school. The boys are required to continue their learning from the home context. While health is the priority, education also is important. School is part of every child's normal day. The family want to help the boys stay on top of schoolwork as much as possible and plan for when they can return to school. Not only does staying connected to school bring academic, cognitive, psychological, and social benefits; it is also a legal right under the Disabilities Discrimination Act 1992 & Disability Standards for Education 1985. Children with chronic illness and/or disabilities are entitled to educational support. The family asked the school for reasonable modifications and accommodations to support the boys' opportunity to access their learning.

**If students cannot attend school for medical reasons, (including a chronic health condition or a compromised immune system) they will be supported**

Schools will continue to support students who cannot attend for medical reasons with learning materials and guidance. Remote learning will remain available for students with chronic health conditions or compromised immune systems.

Schools may need to work one-on-one with the caregivers/parents of vulnerable students to manage their risk, and if/when they return to school. Additional measures, such as the provision of additional hand sanitiser or providing hand hygiene prompting or assistance, may need to be put in place to support vulnerable students if appropriate.

<https://education.vic.gov.au/parents/Pages/Physical-distancing,-health-and-hygiene.aspx>

Mum and Dad have a strong desire to work in partnership with the school to support the learning needs of both boys so that they can access quality learning opportunities equal to that of their peers. The learning pack provided to the boys was not sufficient in scope and challenge to meet and support the boys' learning at their point of need. The school said they could not support the boys' learning in any other way.

A meeting was finally organised. During the meeting it became evident that this school had no knowledge of the Disability Standards for Education.

## Autism Goals ASD School Advocates:

### █'s Experiences Lived by Many Others:

#### Excerpts:

#### These are excerpts shared with Autism Goals Facebook Page:

"I've got another one for you. Said to me this week by the Principal with 2 Ed Dept Reps also involved in the meeting "no one wants to work with your son".

(SD)

"Or Principal "have you thought about sending him to another school"..."yes every day but every school I've called won't take him because we are out of zone"... the department won't help you move schools"... principal "he's not welcome in a classroom at our school have you thought about moving schools?"

(RG)

"My oldest son has been told that next year he has to attend main stream high school (he is currently grade 6, so year 7 next year) as he scored 71 on his IQ test. He reads at prep level and can't write properly or so simple maths..... how the heck is ge going to survive in high school?"

(RD)

My son refused to go to school due to extreme anxiety. I would ring the school each morning asking for support. One afternoon, while I went to the shop and left my son with his elder sister, I got a phone call from the police. The Principal called the police on my son for not attending school. I said to them, I have been asking for support. Go to the house and take him to school. Maybe you can achieve what I cannot. The Police said, No, we will be telling the school, this has nothing to do with us"

(PA)

A █ Principal called the police into the school to confront a child having a meltdown. This child is diagnosed with Post Traumatic Stress as he witnessed family violence over many years. The police would often be called by neighbours when they heard the violence. Police are a trigger for this young boy.

(PA)

We can provide many illustrative experiences of how children with disabilities are not being supported by our schools and are in fact consistently discriminated against. These children's families are at breaking point and our schools generally are not only unfamiliar with the Disability Standards for Education, they do not know they exist.

A handwritten signature in blue ink, appearing to read 'Pauline Aquilina'.

Pauline Aquilina  
Senior Advocate & Manager  
School Advocates for Kids with ASD  
(Electronically Signed)